

Articles of Understanding: GRASP, and the word “Cure.”

Contribution by Michael John Carley, Executive Director, GRASP.

When my son and I were diagnosed with Asperger Syndrome (AS) one week apart in late 2000, I had no idea what kinds of debates were ongoing in the autism world. I thought initially that the autism world would all think the same: “How can they not, given that there’s so much at stake?”

But they don’t. There are hot debates about methods, ethics, and theories—many more so than those Alison and I will touch on with this exchange. And these conflicts are probably a good thing, not a bad thing, even if it complicates matters. For in the grand scheme of things, we still know relatively very little about “all this autism stuff” and these discussions are really the correct, Darwinian road that we should all be on. The problem has only been where the debates have become *so* divisive; where one side’s opinion has so invalidated the experiences of the other. *How* the disputes are played out can be vastly improved upon. And this exchange with AutismSpeaks is a welcome opportunity to rectify some of the hurt that folks on both sides of this debate have experienced.

What I’m going to try to do is outline where we see the divisions existing, and then tell you why GRASP, and maybe other peer-run autism

organizations (in other words, organizations run by adults on the spectrum) believe the way we do.

Where the disagreement lies

Yale's Fred Volkmar once used the words "lumpers" and "splitters" to define the two camps. I like these terms.

On one side are the splitters who think Autism and AS can be clinically separated. On the other, the lumpers, who feel the autism spectrum is all one and the same only with extreme ends, and a vast gradient in between.

Both lumpers and splitters would agree that if Albert Einstein (among many others) really did have AS, as people now say he did, then that's certainly not what people normally associate towards someone severely autistic who may be completely non-verbal. But while no one would want to have "cured" Albert Einstein of *anything*; if the lumpers are right, then that is exactly what we are saying—and this is where the two disagreements become one.

Splitters use the word "cure" believing that autism is a terrible thing to happen to a person, whereas AS, while presenting difficulties, is believed to be not so terrible, and maybe doesn't warrant use of the word. Lumpers (like us) do not believe in the opposite, i.e. that AS is somewhat terrible and/or that autism is not. Rather, they/we believe that the answers are far more complex.

The word “Cure,” like the word “disease,” has historically reflected conditions, syndromes, and diagnoses that are *acquired*, meaning that you got it from somewhere after you were born. Now granted, genetic alteration—as proven by a Welsh lamb a few years ago—is not the impossibility we once thought it to be. And depending on what dictionary you’re consulting, the descriptions of these words may not match the populist manner in which they are used. But in general, most people who believe that autism and AS are genetic do not use the words “cure” or “disease” because they feel primarily that what you were born with—i.e. your genes—you will die with. However, if you *do* believe that autism is acquired, then the word would seem to be medically appropriate.

That’s the medical side to the terminology. But there’s an ethical side too: Who gets to determine what words are used?

This answer too may reflect one’s identity as a lumpers or splitter. In other words, if our ideas of autism strictly revolve around those who are primarily non-verbal, then in an age when we have not yet learned to communicate with the non-verbal autistic, we do not know what terms they would *like* us to use. Therefore, under these ideas, they have to be spoken for by others.

But confusing things further, what if, through therapies and treatments, they *become* verbal? Has their diagnosis then changed?

The authors of the DSM-IV*, for instance, will readily admit that the definitions described for AS and autism do not accurately reflect the world

of adults being diagnosed late in life. These adults, coming from pasts of misdiagnosis, or being thought of previously as quirky, schizophrenic, eccentric, things far worse...these adults can be identified for the symptoms they have, and, for the symptoms they don't have as described in the book; much the same way children are diagnosed. But the book fails the adult diagnosee in that a 3rd category of behaviors—the symptoms they *once* had, but that either through peer pressure, labor...etc. they somehow altered or ironed out of their system—can't be taken into consideration with 100% accuracy.

**The Fourth edition of the Diagnostic and Statistical Manual, the clinical reference book used to diagnose us all by psychologists, psychiatrists and the like.*

If that individual doesn't have the symptoms *anymore*, the question then becomes: are they to be thought of as cured?

Is your head spinning yet? After three years in this job, I promise you: My head never stopped.

I won't profess to you, as someone with AS, that I clearly know what's going on inside the head of what might be your non-verbal daughter or son sitting there in their own world. But I do feel there's more going on inside that head than we, myself included, usually give their credit for being. We just don't see it, so it's hard to believe. Furthermore it's not on a level we understand (yet), and because we love them, this hurts. Obviously, we want to bond with those we love, not think of them as, at best, awe-inspiring mysteries.

As is our nature, organizations of people on the spectrum will focus in on the suffering of people on the spectrum, just as parents organizations will hone in on the suffering of other parents. Both sides learn a lot from one another (which is why GRASP proudly partners with many parents organizations) but what helps parents is often mistakenly spun as helping the autistic or “aspergian” individual (and, to be fair, vice versa). No one can know for sure but many people from our community believe that many non-verbal individuals are quite content in their world, especially if they have good supports and are encouraged to think positively about themselves. The burdens of the families, however, revolve around a myriad of potentially traumatizing circumstances: Financial concerns, deteriorating marriages, addressing neglected siblings, one parent having to quit a job to stay at home to take care of the affected individual; and this is all exceedingly hard, traumatic, life-altering stuff. But the tragedy is so often due to our expectations. There is no fault in this—I face it too as a parent—but you could frankly argue that our problems might have more to do with the playing field autism found itself on, and not with autism itself.

Lastly, are all these diagnoses terrible things to have, or not so terrible things to have? We’re certainly getting mixed messages these days. For examples, there’s:

- the movie about the autistic boy making the track team
- email groups that heavily criticize verbal adults on the spectrum who call themselves “autistic”
- stories describing autism as an epidemic

- books describing Thomas Edison, Thomas Jefferson, Emily Dickinson, Andy Warhol...etc. as being on the autism spectrum
- an educational internet campaign describing the various contraptions a very affected person with autism wears inside the white-walled room where she is pictured
- ESPN showing footage of an autistic kid hoisting 20 in a basketball game.

I could go on...

But instead of answering the question is it terrible or is it not so terrible, maybe the mixed messages are exactly what *should* exist? Or, would it be better if autism and aspergers were vastly different so that these issues wouldn't be so confusing?

It's probably very traumatic for the parent of the severely-affected child to be lectured on the immense potential inherent in the brain and ability of a person on the spectrum. If, when they ask for help, they were to be told no, because their child might have a noble prize in him, I can imagine fewer injustices that would be larger than that. Wouldn't that seem to insultingly invalidate all the hardship they were going through?

Wouldn't it also be equally scary for someone on the spectrum who is desperately seeking positive self-images to be lectured by the world that his life will be, or is, awful?

Why

All sides, not just GRASP and AutismSpeaks, have well-educated clinicians to turn to for quotes or studies to cite. GRASP can quote the work of Dr. Tony Attwood, others might cite passages from Catherine Maurice’s “Let Me Hear Your Voice.” The Yale Child Study Center never uses the word cure, but they do believe in a split between the diagnosis . . . Dr. Simon Baron-Cohen, also, has views of his own too unique to compartmentalize . . . so one can’t even ask “which side are you on?” because the number of sides is too numerous to count. GRASP’s own Board of Directors even, is capable of a spirited internal dialogue on these matters, albeit in the spirit of mutual support and respect.

In the grand scheme of things, when there is so much still to be learned about autism, we *know* very little. This doesn’t, and shouldn’t curtail our firm beliefs, as that’s how progress is made, but it is something quite healthy to keep in the back of one’s mind.

GRASP primarily believes that Autism, Aspergers, PDD-NOS (Pervasive Developmental Disorder—Not Otherwise Specified)...etc. will eventually be found to be variants of one and the same diagnosis. The main three reasons why we believe this are as follows:

1. Quite simply, it hasn’t been conclusively proven otherwise.

2. If the autism spectrum runs from A to Z; and if Albert Einstein is “A,” and that non-verbal individual is “Z” (using the ability to succeed in the world as our spectrum), then where is the Autism/Asperger cut-off? Is the line in the sand drawn at “M” or at “N”?

Although GRASP does not have non-verbal folks participating in our support groups, the problem for us is that, in addition to the “M”s and the “N”s, we see plenty of “G”s and “T”s along the functionality spectrum. And we see no dividing mark. We see a gradient. We see a gradual progression of abilities and challenges that flow into each other quite naturally. Also, if there was a dividing line between “M” and “N,” what if “N” was able to improve enough to cross over into “M”? Again, the diagnosis can’t change, but the affected individuals almost always *do*, and often quite dramatically.

3. Prior attempts at clinically marking the separation have failed under the microscope of experience. If, for instance, we go by the adage that if one was talking at 36 months, it’s AS; and if not, it’s autism...then my son has autism. But my son plays little league, guitar, and now has sleepovers with his friends . . .

In GRASP’s networks there are teachers, Ph.D.s and city workers diagnosed with autism; and there are contradictorily severely-challenged folks diagnosed with AS living in institutionalized settings. The influence of good vrs. inadequate supports in one’s life (family life, and education, as well as clinical support) will go a long way towards determining that person’s abilities, where they fall on the spectrum, and how happy they will be.

That educated diagnosis will always help as well. But even if AutismSpeaks and GRASP were to agree on the words that should be used, the psychiatric community may fail us both. Currently, there is too much inconsistency amongst the diagnostic world for us to become too married to the diagnoses we are often given. Despite their degrees, there are a lot of inadequately informed clinicians out there.

GRASP also believes in the genetic nature of autism. Environmental, man-made factors may *exacerbate* existing autism (that simply hadn't shown itself prior), or trigger it, just like a sensory integration issue‡ would. But it's when people use the word *causes* instead of *exacerbates* that we have to say we disagree.

‡ *i.e. a strong sensitivity to certain smells, a reaction to fluorescent lighting, a highly individualized response to unique sounds...etc. Almost everyone on the autism spectrum is believed to have at least one sensory integration issue.*

Following in this path, if GRASP is correct and autism is genetic, we then conclude that to use the word “cure” is medically inaccurate.

In truth, the context of the word “cure” could be infinitely more complex than even GRASP would like. The rare but frightening regressive features that can surface are the outcome of unknown causes that may include genetic and environmental combinations. Also, autism *was* an outcome of a separate condition called “PKU” (Phenylketonuria) which actually has been either “cured” or treated effectively. These admittedly complicate our arguments, even if these more specialized issues are not part of the

mainstream language. But leaving the medical world for a moment, let's move to the other portion of the "cure" debate: the ethical component, because that's where we feel our arguments are the strongest.

The DSM-IV came out in 1994, and under the new definitions of the autism spectrum, perhaps over a million more Americans might qualify for an autism spectrum diagnosis than did prior. The generations of people once thought of as strange, strangely charming, as geniuses, or failures...etc. who otherwise never would have qualified, myself included, have greatly influenced the alarming statistics we hear nearly every day (such as the 1 in 166 figure cited from the U.S. Government Center for Disease Control) as has far greater public awareness.

But this expansion of who qualifies means that autism has found its way into the world of the verbal, of people who are able to read what's being said about them, and able to give feedback about their feelings towards how they are being described. And GRASP feels that it is *these* individuals who should be dictating what words are used to describe them—not the doctors and researchers. Even if we at GRASP are completely wrong as to the medical accuracy of such words, do Caucasian people get to tell African-Americans what words should and should not offend them? Should Latino women get to tell Asian men what they have a right to get upset about? Words hurt. And almost every one of our folks admits feeling unwanted to some degree when a well-meaning person tells them they hope there's eventually a cure for what they have. Many of our folks, frankly, feel that anything with a prefix of "dis" is bound to have a psychologically-negative effect—all in good time—but the point here for us is that our population is

having a hard enough time finding positive self-imagery. They want to be respected for who they *are*, and these words, in addition to our population's already-obvious obstacles, make things far worse.

Adding to that negative iconography is that when adults on the spectrum voice their objection to these words, and people respond by either not hearing, or by pretending not to hear, these objections; then their feelings become invalidated too. The use of the word “cure” has been a universally-denounced term amongst our folks. The researchers may argue truthfully that it's not intended to hurt the feelings of people on the spectrum, but is it their call?

Autism, whether we like it or not, does not mean just the severely-affected, non-verbal person anymore. That person is a component to be taken into BIG consideration, most assuredly, but the spectrum got more confusing in 1994, and we believe this also is a good thing, not a bad thing; a “thing” that puts us on the road to knowing more about this thoroughly confusing and complex condition(s?).

We all have to adapt every time there's new knowledge. And this means that whether one is more comfortable with pre-1994 definitions of autism, or with the 2006 definitions, the terminology will change further—many times over. Whatever words we're using now will change. And because we are experiencing such an outpouring of knowledge and public education (thanks in part to both our organizations), we often get the idea that we're close to finding out all that we are meant to know. Again, I'm no clinician, but my gut tells me that we've made a quantum leap from knowing, say, 13% of

what we're destined to discover about the autism spectrum, to 17%. Now, pretending that my uneducated and figurative "gut" numbers are true; that truly is a huge jump to be done in so short a time span. But the end result is still 17% out of 100%. We have far to go. We are all going to have to be very flexible even if—given the suffering that everyone on all ends of the spectrum is enduring—we don't want to be.

Parallel stories of coping, meanwhile, will help.

Thank you all for listening.

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